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Comparison of two Dutch follow-up care models for spinal cord-injured patients and their impact on health problems, re-admissions and quality of care

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Objective: To evaluate whether transmural care for people with spinal cord injury living in the community has more impact on health outcomes than traditional follow-up care within the Netherlands.

Design: Quasi-experiment with 12 months of follow-up.

Setting: Eight Dutch rehabilitation centres.

Subjects: Thirty-one patients who received transmural care in two 'experimental' rehabilitation centres were compared with a matched sample of 31 patients having received 'usual follow-up care' in six other rehabilitation centres.

Intervention: The core component of the transmural care consists of a transmural nurse, who 'liaises' between former patients living in the community, primary care professionals and the rehabilitation team. The transmural care model provides activities to support patients and their family/partners and activities to promote continuity of care.

Main measures: The prevalence of pressure sores and urinary tract infections; the number and duration of re-admissions to hospital and rehabilitation centre due to pressure sores, bladder and bowel problems; and the experienced quality of follow-up care.

Results: The transmural care, as implemented, did not influence the health outcomes. The prevalence of pressure sores, urinary tract infections and the number of re-admissions (due to pressure sores, bladder and bowel problems) was respectively 13, 13 and 4 in the intervention group versus 14, 15 and 6 in the usual follow-up care group. Since the transmural care had been incompletely implemented and there were methodological and practical limitations, we formulated no final conclusions regarding its effectiveness.

Conclusion: Implementing the transmural care model strictly according to protocol may improve its effectiveness.

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Introduction

People with spinal cord injury living in the community often have health problems, such as bladder and bowel problems, spasms, pain, and pressure sores.¹ In the Netherlands, after discharge from inpatient rehabilitation, daily medical and nursing care for patients with spinal cord injury is transferred from the rehabilitation centre to primary health care. However, because spinal cord injury is a rare condition with an incidence of traumatic spinal cord injury of 10.4 per million per year who survive the acute stage in the Netherlands,² primary health care professionals only sporadically see patients with spinal cord injury in their practice. This means that they might not have much opportunity to expand their knowledge about the specific care such patients require. The professionals in rehabilitation centres, on the other hand, are limited in their possibilities to give follow-up care, due to the limited payment they receive from health service insurers for this kind of care. For these reasons, until recently, life-long care for people with spinal cord injury was poorly developed in the Netherlands. The need for effective interventions aimed at the prevention and early treatment of health problems after discharge has been reported frequently.^{1,3–8}

We developed a transmural care model for people with spinal cord injury after discharge from rehabilitation to support patients and professionals involved in making the transfer from inpatient rehabilitation to primary health care. Transmural care refers to care given ‘through the (virtual) walls’ of the existing health care system and is most often directed toward bridging the gap between different levels of care providers.⁹ Although the transmural care concept is not often used outside the Netherlands,¹⁰ problems with continuity of care are not specific to the Netherlands; they occur in many other countries too.^{11,12} Integrated care is a more common term which refers to the integration of health care, social care and related services.^{11–13} It is more comprehensive than transmural care since transmural care generally does not include the whole

care process of patients and is focused on one or two crucial transition steps between different types of health care provider.⁹

The primary goal of our transmural care model was to reduce the number and severity of health problems. It was expected that the transmural care model could positively influence their prevention and treatment. This quasi-experimental study aimed to determine whether people receiving this transmural care had better outcomes than people receiving ‘usual’ follow-up care.

Methods

Design

The intervention study has a quasi-experimental longitudinal design. Patients who received the transmural care in two ‘experimental’ rehabilitation centres (De Hoogstraat and Hoensbroeck) were compared with patients who received ‘usual follow-up care’ in six other rehabilitation centres. Effects of the transmural care programme were evaluated by comparison of outcomes in both groups one year after discharge from inpatient rehabilitation. For each subject in the experimental group, a subject in the control group was selected who was similar with regard to level and motor completeness of the spinal cord injury, gender and age. Matching between the groups was done at the 12-month point, to include only those for whom 12-month follow-up data were available.

Participants were recruited from the Dutch research programme ‘Physical strain, work capacity, and mechanisms of restoration of mobility in the rehabilitation of people with spinal cord injuries’ (www.fbw.vu.nl/onderzoek/A4zon/ZONenglish)¹⁴. This programme consists of 18 research projects conducted in a network of eight rehabilitation centres specialized in the rehabilitation of people with spinal cord injury and five research groups. This study concerns one of the 18 research projects and focuses on follow-up care for people with spinal cord injury after finishing clinical rehabilitation. For the patients to be included in this effectiveness study, the same

inclusion criteria as in the above-mentioned research programme were applied:

- 18–65 years of age
- Spinal cord injury, both tetraplegia and paraplegia, American Spinal Injury Association (ASIA) impairment scale A–D,¹⁵ in some way wheelchair dependent
- The injury itself is stable (no progressive disease)
- Receiving rehabilitation treatment for the first time (no re-admissions).

Inclusion of 60 ‘experimental’ patients and 60 ‘control’ patients was expected.

Intervention

The intervention and usual follow-up care groups differed with respect to the intensity of follow-up care given by the rehabilitation centre after conclusion of clinical rehabilitation. Day-to-day medical and nursing care in both groups is usually given by primary care professionals.

Usual follow-up care group

The participants in the usual follow-up care group were able to make use of periodic outpatient visits to the rehabilitation doctor at their rehabilitation centre. During these visits a comprehensive assessment of functioning (i.e. physical, psychological, social and communicative functioning, and functioning regarding activities of daily living) was performed and, if necessary, interventions were applied or other forms of support given.

Intervention group

In addition to the usual follow-up care by the rehabilitation doctor at the rehabilitation centre, the participants in the intervention group had access to transmurals care for at least one year after discharge. The core component of the transmurals care consists of a transmurals nurse as liaison between people with spinal cord injury living in the community, primary care professionals and the rehabilitation centre. The transmurals nurse is a member of the clinical rehabilitation team (she

also works as a nurse at the spinal cord unit) and is engaged for 8 hours a week to perform four main tasks:

- to support people with spinal cord injury and their partner/family with their health problems, which come within the scope of the nursing discipline;
- to support primary care professionals with the specific care of people with spinal cord injury;
- to promote continuity of care between primary care professionals and the rehabilitation team;
- to give feedback and initiate improvements in care for the rehabilitation team, based on the experiences with patients.

This transmurals care could be used by all patients with spinal cord injury in the two ‘experimental’ centres who had been discharged between January 2002 and July 2003. The effectiveness study, however, only included patients who were also included in the national research programme ‘Physical strain, work capacity, and mechanisms of restoration of mobility in the rehabilitation of persons with spinal cord injuries’.

Appendix 1 shows the job description for the transmurals nurses, containing activities to support people with spinal cord injury and their family/partners and activities to promote continuity of care. A detailed description of the project is given elsewhere.¹⁶ A process evaluation was performed to monitor the level of implementation of transmurals care in both experimental centres.¹⁶

Before the start of our intervention and every year afterwards, we monitored the contrast in follow-up care between the experimental and control centres by interviewing their rehabilitation doctors and/or managers about the content and developments regarding their follow-up care. Subgroup analyses were performed in case the contrast decreases between the intervention and usual follow-up care groups regarding the follow-up care.

Outcome measures

Primary outcome measures

Since pressure sores and bladder problems frequently occur and are important causes for

re-admission in hospital and rehabilitation centres,^{17–19} the primary outcome measures were as follows:

- The prevalence of pressure sores and urinary tract infections reported during the first year after discharge. For these complications the patients were asked to indicate whether or not they had faced the problem during the previous 12 months. For pressure sores, additional questions were asked about the type, location and seriousness.
- The number and duration of re-admissions to hospital and rehabilitation centre due to pressure sores, bladder and bowel problems in the first year after discharge.

Secondary outcome measures

The secondary outcome measure was the quality of follow-up care experienced, since it is recognized that the patient's perspective is as important and valid as the clinician's perspective in monitoring health care outcomes.^{20–23} The patients were asked to judge 15 items regarding the quality, continuity and coordination of care (see Table 4). Per item they had to indicate whether this aspect of follow-up care in the first year of discharge was either 'open for improvement' or 'good'.

The intervention started in January 2002 and ended in June 2004. Participants were interviewed (primary outcome measures) and received self-administered questionnaires (secondary outcome measure) at discharge and one year after discharge.

Statistical analysis

Descriptive analyses were performed to describe the outcomes. Data analysis focused on comparison of the intervention group with the usual follow-up care group. To compare the quality of follow-up care experienced for each item the percentage of participants that judged the items as 'open for improvement', was calculated. Differences regarding the outcomes measures in the intervention and usual follow-up care groups were tested with the Fisher exact test ($P < 0.05$).

Results

Participants

Figure 1 shows the flow of the participants through our intervention study. Overall, 149 people met the inclusion criteria. The transmural care group consisted of 39 people and the usual follow-up care group consisted of 110 people. Six people died during the 12 months of follow-up, three were excluded from follow-up since they were not dependent on a wheelchair anymore, and four were not able to visit the rehabilitation centre for follow-up measurements due to secondary complications. Non-medical reasons for withdrawal were lack of motivation ($n = 14$) and address unknown ($n = 7$). There were 31 participants who received the intervention and who were followed up at 12 months. There were 84 participants with follow-up measurements in the usual follow-up care group. Matching was applied with regard to the level and motor completeness of the injury, gender and age. Twenty-eight participants in the intervention group (90.3%) were matched to participants of the control group within five years of age and same sex and same level and motor completeness of the injury. For two matched pairs of respondents' ages differed more than five years. Another matched pair of respondents differed regarding the level of tetraplegia and age.

Table 1 shows the general characteristics of the intervention group and the matched usual follow-up care group.

The intervention

Although the transmural nurses spent most of their time on the individual support of patients after discharge (activities 1–2 in Appendix 1), only 15 patients (48%) received the number of contacts indicated in the protocol (6 contacts). The remaining patients had fewer contacts and two patients (6.5%) chose to organize their care autonomously and to contact the transmural nurse on their own initiative. On average there were 4.3 contacts (SD 2.4) per patient in the first year after discharge. In one of the 'experimental' rehabilitation centres the number of contacts (average of 3.4 versus 5.2, SD in both centres 2.2) and the variation in types of contacts were fewer compared

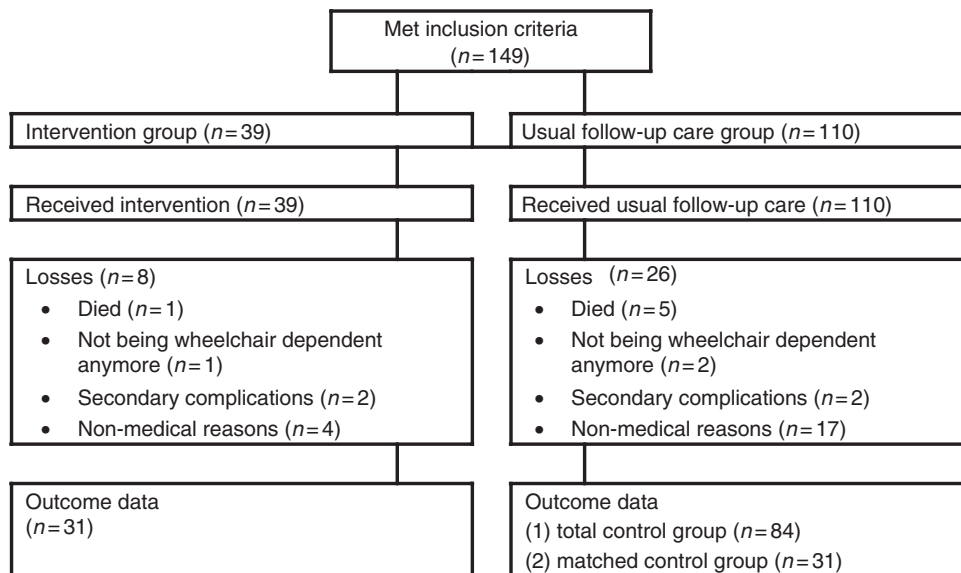


Figure 1 Flow of participants through this intervention study.

Table 1 Subject characteristics

	Transmural care group (N=31)	Matched control group (N=31)
Age, mean, years (SD)	37.8 (13.8)	036.1 (13.6)
Men (N)	24	24
Level and type of injury (N)		
Complete tetraplegia (C1–C5)	2	2
Incomplete tetraplegia (C1–C5)	1	2
Complete tetraplegia (C6–T1)	5	5
Incomplete tetraplegia (C6–T1)	5	4
Complete paraplegia	15	15
Incomplete paraplegia	3	3
Cause of injury (N)		
Traumatic	27	26
Non-traumatic	4	5
Average clinical rehabilitation, days (SD)	270.7 (123.6)	294.1 (168.2)

with the other ‘experimental’ rehabilitation centre. The number of interventions per patient were also different in the two ‘experimental’ rehabilitation centres (average of 1.3 versus 2.3, SD in both centres 1.5). Pressure sores were the most common health problem for which interventions

were applied, followed by bladder and bowel problems. On average, the transmural nurses applied 1.7 interventions per patient (SD 1.6); eight patients (25.8%) did not receive any intervention. Compared with the individual support of patients, in both rehabilitation centres, little time was paid to activities to promote continuity of care (activities 4–9 in Appendix 1).

Outcomes

Table 2 shows the prevalence of urinary tract infections and pressure sores during the first year of discharge. The prevalence of these problems was not significantly different in the two study groups. In addition there were no significant differences between the groups regarding re-admission rate in hospital or rehabilitation centre due to pressure sores, bladder and bowel problems in the first year after discharge (Table 3). There were also no significant effects found in the prevalence of spasms, pain, oedema, respiratory tract infections, autonomic dysreflexia, low blood pressure and increasing weight.

In the intervention group between 27 and 29 participants gave their opinion on the quality

of follow-up care for each item; in the usual follow-up care group between 20 and 23 participants gave their opinion on each item. The quality of follow-up care experienced was not significantly different in the two study groups (Table 4).

There were also no significant difference in the outcome measures between the intervention group and the total usual follow-up care group ($n = 84$).

Table 2 Prevalence of health problems during the first year after discharge

	Transmural care group ($N = 31$)	Matched control group ($N = 31$)
Urinary tract infections (n)	13	15
Pressure sores (n)	13	14
Pressure sores per location (n)		
Heel	2	5
Ankle	2	0
Hip	0	0
Buttock	5	3
Coccyx	6	4
Other location	3	4
Bed rest needed due to pressure sores	9	5
Bed rest due to pressure sores, mean, days (SD)	45.2 (49.9)	64.8 (37.2)
Grade of pressure sores (n)		
Grade I	6	2
Grade II	7	6
Grade III	5	6
Grade IV	0	2

During the intervention period, three out of six 'usual follow-up care' rehabilitation centres extended their follow-up care, and although the content of those follow-up programmes differed from our intervention, some components showed similarities. However, subgroup analyses did not show differences in outcome between the intervention group and participants who did not make use of follow-up care innovations in the usual care rehabilitation centres.

Discussion

This quasi-experiment showed that transmural care for people with spinal cord injury, as implemented, did not significantly reduce the number of health problems and re-admissions to hospital or the rehabilitation centre due to these health problems. Furthermore, the transmural care did not significantly improve the quality of follow-up care as perceived by the patients.

There could be several explanations for not finding our intervention to be effective. First, the process evaluation showed that the transmural care was not fully implemented as planned.¹⁶ Although the transmural nurses spent most of their time on the individual support of patients after discharge (activities 1–2 in Appendix 1), the number of contacts and interventions being applied in the first year after discharge did not

Table 3 Re-admissions in the first year after discharge

	\bar{n}	Transmural care group ($N = 31$) Days of re-admission, mean (total)	\bar{n}	Matched control group ($N = 31$) Days of re-admission, mean (total)
Re-admission in hospital due to				
Bladder or urinary tract infections	1	10 (1)	2	5.0 (10)
Bladder surgery	0	0 (0)	1	1.0 (1)
Bowel regulation problems	1	10 (1)	2	16.0 (32)
Pressure sores	0	0 (0)	0	0 (0)
Re-admission in clinical rehabilitation due to				
Bladder or urinary tract infections	0	0 (0)	0	0 (0)
Training after bladder surgery	0	0 (0)	0	0 (0)
Bowel regulation problems	0	0 (0)	0	0 (0)
Pressure sores	2	21 (42)	1	7.0 (7)
'Re-training'	0	0 (0)	2	38.5 (77)

meet our expectations (the protocol indicated six contacts). There also was a clear difference in implementation in the two rehabilitation centres. In one centre the number and the variation in types of contacts and the number of interventions were fewer compared with the other 'experimental' rehabilitation centre. In both rehabilitation centres little attention was paid to activities to promote continuity of care (activities 4–9 in Appendix 1) compared with the individual support of patients. Second, the contrast between the intervention and the control group regarding follow-up care decreased during the intervention period because three out of six 'control' centres extended their follow-up care. Third, the follow-up period of 12 months might have been too short. In the first year after discharge patients possibly easily consult the rehabilitation team on their own initiative in case of questions and/or

problems. With increasing time after clinical rehabilitation patients might be more reluctant to consult their rehabilitation team. The presence of a transmural nurse then might be of great importance and might have more effects. Finally, our study population ended up rather small (only 62 (52%) of the targeted inclusion of 120 persons), which clearly reduced the power to observe significant differences. We were not able to extend the inclusion of patients, since our study was linked to the national research programme 'Physical strain, work capacity, and mechanisms of restoration of mobility in the rehabilitation of persons with spinal cord injuries', which involves all spinal cord injury rehabilitation centres in the Netherlands. However, since we found hardly any differences, we would not expect to find significant differences by increasing the size of the study population.

Table 4 Experienced quality of follow-up care

Items judged as being 'open for improvement'	Transmural care group (N=27–29) % (n)	Matched control group (N= 20–23) % (n)
The degree to which the professional caregivers are acquainted with my (health) problems	28 (8)	36 (8)
The degree to which I am involved in decisions about the help or treatment I receive	21 (6)	14 (3)
The degree to which the professional caregivers can be reached by phone	28 (8)	48 (10)
The degree of knowledge professional caregivers have regarding spinal cord injury	45 (13)	52 (12)
The degree to which the professional caregivers keep their appointments/agreements	17 (5)	30 (7)
The degree to which my partner or family are involved in dealing with the consequences of the spinal cord injury in my home situation	21 (6)	18 (4)
The degree to which the professional caregivers attune their care in case my situation changes	21 (6)	19 (4)
The degree to which professional caregivers stimulate me to organize my care as autonomously as possible and desired	17 (5)	19 (4)
The degree to which the care meets my needs	21 (6)	32 (7)
The degree to which the professional caregivers collaborate with each other	36 (10)	38 (8)
The degree to which the professional caregivers inform each other about the care I receive	38 (11)	38 (8)
The degree to which different professional caregivers harmonize their care	36 (10)	48 (10)
The degree to which professional caregivers refer me to another professional caregiver if necessary	36 (10)	45 (9)
The degree to which the advices of professional caregivers are in line with to each other	38 (11)	50 (10)
The number of professional caregivers from whom I receive care	15 (4)	25 (5)

The results of our evaluation were in sharp contrast with the experiences of the transmural nurses and the rehabilitation teams.¹⁶ According to the nurses, the strength of the transmural care lay in the possibility of giving support to patients and primary care professionals after discharge. They felt that their support was appreciated and that it created an opportunity to detect problems and to intervene in an early stage. They had the impression, for instance, that they had been able to prevent re-admissions because of pressure sores. The fact that more participants in the intervention group held bed rest because of pressure sores, might indicate a more effective and timely treatment. The transmural nurses also strongly believed that their advice regarding bowel problems increased the quality of life of several patients. The rehabilitation teams at the 'experimental' rehabilitation centres were also satisfied with the transmural care and decided to continue it after the study period. Three out of six 'usual follow-up care' rehabilitation centres, in addition, extended their follow-up care, showing a growing appreciation of its importance. In our opinion it is important not to be discouraged by the results of one of the first effect studies of follow-up care.²⁴

The contrast between the results of this evaluation study and the experiences of the rehabilitation teams creates an interesting dilemma: professionals are positive about the intervention and implement it, but the evidence indicates that implementation of the present intervention should probably be discouraged. As indicated, our intervention seems not to have been implemented 'strongly enough'. Therefore, we think that professionals have two options to choose from: not implementing it or implementing it more strongly without making 'compromises', otherwise it would probably make little difference, as our study indicates.

Although the need for follow-up care has been increasingly recognized,²⁵⁻³⁰ our systematic review²⁴ identified only a small number of follow-up care programmes, the effects of which had usually not been studied properly. This review, therefore, revealed no clear evidence for the effects of follow-up care programmes on the prevalence of secondary impairments, well-being and the quality and costs of care. Since our transmural nursing care model was inconsistently and

incompletely implemented in both of the 'experimental' rehabilitation centres in our study, and there were also several methodological and practical limitations that hampered our effect evaluation, it was not possible to formulate final conclusions regarding its effectiveness. After all, we do not know what effects might have been achieved if the transmural nursing care had been implemented more strictly. All this contributes to the most important conclusion of this study: there is a need for the development, implementation, well-designed evaluation and publication of follow-up care programmes for people with spinal cord injury, since these people experience serious health problems after discharge. It is important not to view rehabilitation as a one-time event. There should be opportunities for people with spinal cord injury to keep in contact with the rehabilitation centre in the long term, allowing them to get support if health problems arise, and to remain informed about new interventions and technologies.

Rehabilitation professionals should take the lead in optimizing follow-up care for people with spinal cord injury, since rehabilitation teams have the greatest expertise regarding their specific care needs. In our opinion, health care professionals and researchers should continue their efforts to improve the effectiveness, the quality and the efficiency of follow-up care. Evaluation and publication of experiences with other interventions is recommended, since information on the evidence of interventions and barriers and facilitators to change are essential for evidence-based improvements of care.^{31,32}

Clinical messages

- Transmural care for people with spinal cord injury, as implemented, did not influence health outcomes.
- The transmural care model had not been implemented according to protocol.
- Implementing a care protocol should be accompanied with a plan to identify barriers for implementation and to deal with these.

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- 2) To give advice and support after discharge from clinical rehabilitation depending on the needs and the complexity of care by means of (at three weeks, 3, 6, 9 and 12 months after discharge):
 - 2.1) telephone consultations on the initiative of the transmural nurse;
 - 2.2) consultations in the rehabilitation centre (in addition to the periodical outpatient visit to the rehabilitation doctor);
 - 2.3) home visits in case of health problems;
 - 2.4) telephone consulting hours (consultation of the transmural nurse on the initiative of people with spinal cord injury).
- 3) To organize peer meetings after discharge.

Activities to promote continuity of care

Appendix 1 – Job description for the transmural nurses

Activities to support people with spinal cord injury

- 1) To introduce the transmural care before discharge from clinical rehabilitation and to explore the needs of follow-up care, and to make agreements about this (Patients with spinal cord injury are free to decide whether or not to make use of the transmural care).
- 4) To introduce the so-called 'care compass', a little book which contains individual advice of caregivers to the patient, an overview of health services, and information sheets concerning several consequences and complications of spinal cord injury. The patient 'owns' the care compass, but it is also meant to support the caregiving by family/partners and professional caregivers.
- 5) To organize telephone consulting hours for primary care professionals.
- 6) To organize a meeting at the patient's home before discharge with the patient, the primary care professionals of all care disciplines involved with the care after discharge, and the transmural nurse to transfer care, in case of complex care.
- 7) To inform primary care professionals about the transmural care (content and accessibility).
- 8) To organize presentations to primary care professionals to inform them about spinal cord injury, prevention of secondary impairments and the specific care people with spinal cord injury need.
- 9) To organize presentations to the rehabilitation team to inform them about experiences with people with spinal cord injury after discharge and to make proposals for improvement in the clinical care, on the basis of the experiences with patients.